Scott T. Martin. The Federal Goal of Making All Healthcare Records Electronic By 2014: Differing Viewpoints. A Master's Paper for the M.S. in I.S degree. August, 2007. 31 pages. Advisor: Brad Hemminger

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In 2004 President George Bush requested that all patient medical records be in electronic format by 2014. This paper analyses progress in the United States towards the creation of a National Health Information Network to link all aspects of the American healthcare system into one access point where patient's healthcare records can be stored and accessed electronically. It examines the viewpoints of the government, American citizens, software companies, and healthcare professionals and institutions, and attempts to present the current barriers to accomplishing this mission.

It concludes the goal is possible and progress is well underway.

Headings:

Medical records.

Medical Records Systems, Computerized.

Medical records -- Data processing.

Medical records -- Access control -- United States.

THE FEDERAL GOAL OF MAKING ALL HEALTHCARE RECORDS ELECTRONIC BY 2014: DIFFERING VIEWPOINTS

by
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A Master's paper submitted to the faculty
of the School of Information and Library Science
of the University of North Carolina at Chapel Hill
in partial fulfillment of the requirements
for the degree of Master of Science in
Information Science.

Chapel Hill, North Carolina

August 2007

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Introduction

A real push exists today in America to make Healthcare Records electronic. While it is generally considered that electronic healthcare records would be of tremendous benefit to everyone, there is a vast difference between the imagined goals and the actual implementation. The idea that people should own their own healthcare records is juxtaposed with the reality that healthcare institutions maintain a monopoly on them – a monopoly they are not readily willing give up. To understand the dilemmas involved with regards to electronic medical record adoption and the use of Personal Healthcare Records, it is necessary to evaluate the particular viewpoints of:

- the government,
- the American citizens as individuals,
- the software companies, and
- the healthcare professionals and healthcare institutions.

Viewpoint of the Government

The United States Department of Health and Human Services (HHS) provides a variety of services intended to bring healthcare services in the United States into an organized whole that follows government standards such as HIPAA (the Health Insurance Portability and Accountability Act of 1996). On April 27th, 2004 President Bush requested the majority of Americans should have electronic medical records (EMRs) in ten years time and signed an Executive Order[1] to establish a new position within the HHS of National Coordinator for Health Information Technology (known as the Office of the National Coordinator, or ONC) who would advise Michael O. Leavitt, HHS Secretary,

[1] Executive Order no. 13335, "Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator." *Federal Register* 69, no. 84 [April 27, 2004]: 24059, http://www.whitehouse.gov/news/orders/ [accessed August 13, 2007].

about how to improve healthcare in America. Later that year, the ONC released a four part strategy called Framework for Strategic Action[2].

The HHS Framework for Strategic Action has four goals: (1) Informing Clinicians, (2) Interconnecting Clinicians, (3) Personalizing Care, and (4) Improving Population Health. The document is verbose in its description of what these goals mean, but in summary:
1. Informing Clinicians involves helping finance healthcare institutions that cannot shoulder the burden of converting to a paperless institution, and providing them with the information to choose between software developers for their particular needs.
2. Interconnecting Clinicians would establish Regional Healthcare Information Organizations (RHIOs) which would unite healthcare providers and would be government-funded. These RHIOs would in turn be interconnected under a National Health Information Network (NHIN) and would use pre-existing standards developed by the private sector.
3. Personalizing Care would encourage the use of Personal Healthcare Records (PHRs), which would give patients access to their healthcare records. Educated consumers would be able to manage their health information, including remote management with the tools of information technology.
4. Improving Population Health refers to unifying the sharing of information for crisis situations, consolidating results of patient healthcare, and expediting the results of technological and medical developments and the rate they are deployed in healthcare institutions.

The Framework for Strategic Action defines PHRs as "electronic application[s] through which individuals can maintain and manage their health information (and that of others for whom they are authorized) in a private, secure, and confidential environment." In a letter dated September 9, 2005, to Secretary Michael Leavitt of the Department of Health and Human Services from Simon Cohn of the National Committee on Vital and Health

[2] Tommy Thompson and David Brailer, "The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Healthcare Framework for Strategic Action." *Department of Health and Human Services* [July 21, 2004], http://www.hhs.gov/healthit/documents/hitframework.pdf [accessed August 13, 2007].

Statistics (NCVHS), the Chairman Cohn writes "NCVHS found that there is no uniform definition of "personal health record" in industry or government, and the concept continues to evolve. Experts often use the concept of the PHR to include the patient's interface to a healthcare provider's electronic health record. Others consider PHRs to be any consumer/patient-managed health record. This lack of consensus makes collaboration, coordination and policymaking difficult."[3]

Without a uniform consensus it is important to realize that Personal Health Records are not necessarily electronic. The collection of X-rays a private individual keeps in a filing cabinet or safe constitutes a Personal Health Record. Similarly, a Personal Health Record may be kept on a laptop, USB device, or on a website that hosts space for storage of medical information. Without a federally imposed standard, all forms are acceptable. One thing is true, however: the work involved in maintaining them, and very often the cost, is left to the individual.

The costs associated with maintaining Electronic Medical Records, on the other hand, are incumbent on the healthcare institution. An Electronic Medical Record (EMR), also know as an Electronic Health Record (EHR), is a set of data files that all correspond to one individual. The data is stored in an XML (Extensible Markup Language) format similar to HTML that follows a standard developed by Health Level 7, a non-profit volunteer group of medical information technology professionals. Other standards have been developed to store images, such as Digital Imaging and Communications in Medicine (DICOM). In general, all these standards are logical and straight-forward enough to be supported across multiple computer platforms, including Linux, Microsoft and Apple.

Under HIPAA, the way in which medical claims were reported to insurance agencies were standardized *if they are done electronically*. This prevented protected health information from being insecurely communicated across the internet, and adherence to

[3] Simon Cohn, Letter to Michael Leavitt September 9, 2005. *Department of Health and Human Services National Committee on Vital and Health Statistics*, http://www.ncvhs.hhs.gov/050909lt.htm [accessed August 13, 2007].

the standards cut down on the confusion associated with processing insurance claims for everyone. It did not require medical claims to be electronic, nor did it prevent insurance companies or healthcare institutions from communicating by mail. Because the internet is the fastest form of communication, however, automatic billing systems are popular because they save both time and money. Because of these earlier accomplishments under HIPAA, healthcare institutions adopting EMR systems are generally looking for interoperability with their current billing systems.

HIPAA did something else for patients. It required the medical institutions to release their medical records to them. Along those lines, it followed that if a medical institution used all electronic records, the records could be released in the form of a CD. This, perhaps, was the initial attraction to having EMRs: instead of having someone take time off their job to make complicated reproductions of X-rays, lab reports, and paper documents, the entire patient history could be burned onto one CD.

Other laws that are applicable to the sharing of healthcare records are the Stark Laws and the Federal Anti-Kickback laws which prevent referrals between healthcare institutions that can benefit financially, and the Safe Harbors that exempt certain beneficial arrangements.

On July 21, 2004, the same day HHS Secretary Thompson proposed what would later be called the Framework for Strategic Action, Congressman Patrick Kennedy of Rhode Island introduced the "Josie King Act of 2004," H.R. 4880, named for an 18-month old child who died because of preventable medical errors. The prelude to the act has some surprising statistics: In the U.S., 98,000 people die each year as a result of hospital error[4], and 20% of tests are ordered because the previous results are unavailable. The Josie King Act has three parts:

[4] The statistics estimating 98,000 were done in the 1999 by IOM and based on numbers from a 1984 study of New York and a 1992 study of Colorado and Utah. The results were given as percentages and extrapolated to the entire United States. IOM admits the number could be as low as 44,000. A later study in Colorado, published in July 2004 by a consulting firm HealthGrades concluded the number to be much higher: 575,000 deaths across a three year period 2000-2002.

1. "Integrated health information networks allowing all providers, with patient consent, to share health information and providing computerized checks and decision-supports to providers.
2. A better understanding of what constitutes good health care and how to deliver it.
3. Payment systems that reward the quality, not the quantity, of medicine practiced."[5]

Other bills have been proposed by other members of Congress and the House of Representatives with similar plans to subsidize costs for healthcare institutions. At the moment, the Josie King Act is just a bill, not a law[6]. The first part is of particular interest because the phrase "with patient consent," implies by its wording that all Medical Records are owned by the individual, and that individual can "opt out" of the program to share their medical records.

The National Health Information Infrastructure (NHII), another branch of the HHS, lists all the government-sanctioned standards organizations that produce standards for electronic medical records. Most, if not all of them, are non-profit entities run by volunteers whose expert knowledge of writing standards comes from direct experience. Health Level 7, mentioned earlier, is a standards organization that developed the Clinical Data Architecture (HL7 CDA) which codifies how medical records are to be stored for interoperability between various software applications. Software designers write programs that are (or should be) based on these standards, and sell them to healthcare institutions to manage EMR systems. A summary of the standards used in the healthcare industry is presented in Table 1[7]:

[5] Kennedy, Patrick J. "Kennedy Josie King Act (H.R. 4880)" Rhode Island Representative Patrick J. Kennedy Campaign Website. http://patrickkennedy.house.gov/ [accessed August 14, 2007]

[6] It is also a foundation that seeks to reduce medical malpractice by educating caregivers about processes of communication and workflow. More information can be found at www.josieking.org.

[7] National Health Information Infrastructure, chart "Summary: Technology and Standards for Healthcare" Department of Health and Human Services, http://aspe.hhs.gov/sp/NHII/standards.html [accessed August 13, 2007].

Table 1: Technology Standards for Health Care

Messaging Standards	Used For
HL7 CDA/CCR	Clinical data
X12N	Financial data, HIPAA mandated transactions
DICOM	Images
NCPDP	Prescription from providers to pharmacies
IEEE	Bedside instruments, medical information bus

Terminology Standards	Used For
LOINC	Naming standards for interoperablility
NLM/FDA/VA collaboration on RxNorm, NDF-RT	Drugs
CPT, ICD-9CM	Billing
UMLS, SNOMED and others	Clinical

Despite the milestone achievements in standards development, discrepancies do exist. For example, the HL7 Clinical Document Architecture (CDA) was developed separately from a similar standard, the Clinical Care Record (CCR) by ASTM International (formerly the American Society for Testing and Materials), a component group of the American National Standards Institute (ANSI)). The two organizations are working together to create a HL7/ASTM Clinical Care Document (CCD) standard, but the final standards may not be available until 2009 or later.[8]

The NHII documents several reasons why a Health Information Infrastructure is important. These reasons are listed from a government perspective, and would benefit the American people, but not necessarily the healthcare institutions that may have to pay to implement them. They are:

- "To improve *patient safety* (alert for medication errors, drug allergies, etc).
- To improve *healthcare quality* (includes having the availability of complete medical records, test results and x-rays at the point of care, integrating health information from multiple sources and providers, incorporating the use of decision support tools with guidelines and research results, etc).
- For *Bioterrorism* detection (NHII will enable real-time aggregation of health data to detect patterns).

[8] Certification Commission for Healthcare Information Technology, chart "Certification Criteria for Ambulatory EHR Products," http://www.cchit.org/files/Ambulatory_Domain/Ambulatory_Interoperability_-_2007_Criteria_-_First_Draft_-_7-24-06.pdf [accessed August 13, 2007].

- To better inform and empower health care consumers regarding their own personal health information.
- To better understand health care *costs*."[9]

These definitions imply the NHII will become what the HHS Framework for Strategic Action calls a National Health Information Network (NHIN) – the uniting agent between all RHIOs. Such an entity, be it the NHII or the National Committee on Vital and Health Statistics (NCVHS – also part of the HHS), for example, could provide de-identified[10] health statistics on the U.S. population, much in the same way the U.S. Census Bureau provides population statistics, which could be used to note trends in the health of Americans in specific areas.

The concept of RHIOs has evolved within the Department of Health and Human Services (HHS). They have coined a new term: Health Information Exchange (HIE). A similar term is HIEI – Health Information Exchange and Interoperability. These can be defined as "electronic data flow between providers (hospitals and medical group practices) and other providers, and between providers and five stakeholders with which they exchange information most commonly: independent laboratories, radiology centers, pharmacies, payers, and public health departments." A RHIO simply tracks where these EMRs are being stored, but a HIE is actually sharing EMRs and other digital information in a small network. The distinction became important when planning how different types of data would be shared between healthcare institutions.

Another branch within the HHS is the American Health Information Community (ASIC), which was formed by HHS Secretary Leavitt in 2006 to further inform him of the status of Health Information Technology (HIT) in America. It consists of a board of not more than 18 members who work with the assistance of the Office of the National Coordinator

[9] National Health Information Infrastructure, "FAQs about NHII, Department of Health and Human Services, http://aspe.hhs.gov/sp/NHII/FAQ.html [accessed August 13, 2007].
[10] de-identified as defined by HIPPA is not the same as de-identified for research purposes which has further restrictions. The term is being used loosely here to refer to healthcare records stripped of identifying characteristics such as name and social security number, but in reality the restrictions world prevent conclusions more specific than state-wide, annual information to be available to the general public.

(ONC). Together they provide information, a Health Information Technology Certification, and a resource for bringing people together to adopt EMRs.

Recently the HHS asked four separate companies to draft a viable plan to create a NHIN.[11] Each company was required to come up with its own solution, designing a real-life network that would unite multiple Health Information Exchanges (HIEs). They were given the institutions they were to design the network architecture for. The project was supervised by the Office of the National Coordinator – the same department that wrote the Framework for Strategic Action - and perhaps represents the most successful realization of the NHIN so far. The results were analyzed and published May 31, 2007 by a third-party company named Gartner and are called Summary of the NHIN Prototype Architecture Contracts. The companies and the HIEs they linked are as follows[12]:

Table 2: NHIN Prototype Archetecture Contracts

Accenture	
	West Virginia Medical Institute
	Commonwealth of Kentucky's Eastern Kentuncky Health Community
	CareSpark (Tennessee)
CSC-Connecting For Health	
	Indiana Health Information Exchange
	MA-SHARE (Massachusetts)
	Mendocino HRE (California)
IBM	
	Rockingham County, North Carolina - North Carolina Healthcare Information and Communications Alliance (NCHICA)
	Research Triangle/Pinehurst, North Carolina - NCHICA
	Taconic Health Information Network and Community, Mid-Hudson Valley, (New York)
Northrop Grumman	
	Quality Health Network (Mesa County, Colorado)
	Santa Cruz RHIO (Santa Cruz, California)
	University Hospitals Health System (Cleveland, Ohio)

The main purpose of the study was to decide if the NHIN could operate as a "Network of Networks" without having to duplicate EMRs in a central database. All four companies concluded that it was possible, and each presented a computer architecture for doing so with the networks they worked with[13].

[11] Wes Rishel, Virginia Riehl, and Cathleen Blanton, "Summary of the NHIN Prototype Architecture Contracts," Department of Health and Human Services: Office of the National Coordinator for Health Information Technology, 2007, http://www.hhs.gov/healthit/healthnetwork/resources/summary_report_on_nhin_Prototype_architectures.pdf [accessed August 13, 2007].
[12] ibid.
[13] ibid.

Viewpoint of American Citizens and Individuals

The individual patient who wants a PHR can choose from three main formats: paper-based, software programs, and internet services[14]. What they all have in common is they are maintained by the patient, and may benefit or suffer on that merit alone. Paper-based PHRs can consist of a simple folder or folio, or they can be elaborate journals with pockets for holding X-rays. They are cost-efficient and portable, but for security purposes are often left at home when needed most. Computer-based PHRs are the software solution – storing the PHR on a personal computer or laptop. Software programs usually consist of a database-format tables that can have attached digital images. They have several advantages to paper-based PHRs: they take up less space and are easier to duplicate, they are easy to modify and maintain from any computer – perfect for someone who uses computers frequently, and they can be stored on a USB flash drive for easy transport. Often they are self-contained, meaning the medical professional needs only open it like a file on their computer, and may therefore save lives in emergency situations. Unfortunately, these advantages also lead to their disadvantages: security, because it's easy to copy or lose the record; price, they tend to cost more and may require a scanner for images and previous paper-based records; and availability, they will only be used by people who have access to execute programs on a computer, which rules out many low-income families. Most importantly, because the idea of a PHR is so new, no government standard exists for how they store information. Internet services are essentially a website with a login and password where the patient can enter medical data. They usually charge a reasonable subscription rate that varies with the capacity of hard drive space they provide. Simple databases that store pertinent medical information may be cheaper, but they are less likely to provide space to upload scans of X-rays, for example.

[14] American Health Information Management Association, subdivisions based on "How to Choose a PHR Supplier," myPHR.com, http://www.myphr.com/resources/phr_search.asp [accessed August 13, 2007].

According to Caregiver Alliance Web Services there are four types of PHRs: (1) view, (2) tethered, (3) freestanding, and (4) consumer-controlled, interoperable. [15] While these definitions are used to sell their product, The Smart PHR, they still provide an excellent understanding of the PHR market today:

1. View PHRs are the most common, and consist of web accessed health information that mimics the patient's EMR at a healthcare institution. They are usually hosted by the specific institution and accessed by a password given to the patient. They are called "view" PHRs because they are essentially a graphic user interface displaying certain parts of the EMR – those healthcare professionals provide access to the patient: usually lab results, doctor recommendations, and so forth. In some cases the patients can edit certain things, such as change their registered address, "click off" that they have filled a prescription, or e-mail their doctor or a staff member. They are not controlled by the patient, nor are they likely to be interoperable with the PHR at another healthcare institution.

2. Tethered PHRs are the same as view PHRs except they provide access to a regional group of healthcare institutions the patient belongs to. A tethered PHR is hosted by a RHIO of some sort, and as long as the patient is in the network of the RHIO, they can see all those medical records.

3. Freestanding PHRs are completely controlled by the patient. They are stored in an online database, or in software on a laptop, and allow the patient to enter their information, make printouts, and copy the information to a CD or a USB device. The downside of this method is they do not originate with a healthcare institution, so the information in them is what the patient remembers or wants the healthcare professional to see. Likewise, because there are no government-imposed standards like the HL7 standard for EMRs, they are not likely to integrate with the EMRs of the healthcare institutions – the healthcare professionals may have to retype all the information into their system as a result.

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[15] Prosocial Applications, Inc., "What's So Special About the Caregiver PHR?," caregiveralliance.com, http://www.thesmartphr.com/docs/Whats-So-Special-about-the-Caregiver-PHR.pdf [accessed August 13, 2007].

4. Consumer-controlled, interoperable is in concept similar to online banking. You can download the information from your checking account into the software program you use to watch your money; edit, accept and delete your transactions, and report errors to your bank. Similarly, a consumer-controlled, interoperable PHR would allow you to download the EMRs from your medical institution (in the HL7 format), view them in your PHR management software, edit them, and upload them back to your medical institution. Because the medical institutions need to provide the medical records as they were on any given date for lawsuit purposes, this would lead to multiple forms of your EMRs as they have evolved through both patient and healthcare professional editing, and could potentially begin to take up a lot of disk space even though HL7 is relatively compact as a storage format. Caregiver Alliance, who defined "consumer-controlled, interoperable," used it to describe their PHR which can be found at www.thesmartphr.com. It is not the goal of this paper to rate the different PHR systems, but the current list can be found at the website www.myphr.com which is maintained by the American Health Information Management Association (AHIMA).

According to a recent study, 60% of Americans said they would support the creation of a secure online personal health record service. The main reasons cited were checking for errors in their medical record (69%), checking and refilling prescriptions (68%), get lab results over the internet (58%), and communicate via secure email with their doctors (57%). Less than 19% said they would not use a PHR. [16]

With regards to electronic medical records in general, 72% of Americans are in favor (23% oppose) of a nationwide health information exchange for doctors and patients. The primary concern about such an enterprise was security of their medical records. The reasons for supporting it were:

- "It would bring efficiency and accessibility to the healthcare system which they believe would lead to better quality care.

[16] [McInturff, Bill?], "Attitudes of Americans Regarding Personal Health Records and Nationwide Electronic Health Information Exchange. Key Findings From Two Surveys of Americans," Alexandria, VA: Public Opinion Strategies survey for the Markle Foundation, 2005.

- Patients would receive faster and more accurate medical attention in emergencies, because physicians would be able to access a patient's medical history at a moment's notice.
- It would lower healthcare costs.
- It would enable patients to control who has access to their medical information.
- It would decrease errors in diagnosis and medical care." [17]

These results indicate the average person is concerned about their well-being, including both their physical health and the quality of care for the cost of the care. They are also concerned about their privacy and what people, including healthcare professionals, read about them. They are less concerned about bioterrorism and EMR interoperability.

Viewpoint of the Software Companies

Perhaps the most optimistic perspective on the Framework for Strategic Action can be found from the software companies developing the technology. Deploying EMR systems is big business, and they have to design programs that cater to the specific needs of individual medical institutions. To be competitive, software solutions need to provide 24-hour support and software updates to their clients. The market for software solutions is ripe for growth because companies who want to remain small can get a handful of smaller clients and dedicate more time supporting those clients. Likewise large software providers tend to tackle the larger clients, such as hospital complexes that may span multiple blocks, cities or states. Because of the complexity of the healthcare industry, there is rarely an out-of-the-box solution for "going paperless."

In general, EMR systems are interoperable with the HL7 and other requirements set forth by the NHII. The HHS has defined some basic rules for such software systems so the healthcare industry using them can collect payments from Medicare and Medicaid, but the software companies seeking the highest quality recommendation apply for certification from the Certification Commission for Healthcare Information Technology (CCHIT). The CCHIT is a government-ordained institution co-founded by the American Health Information Management Association (AHIMA), the Healthcare Information and Management Systems Society (HIMSS), and the National Alliance for Health Information Technology (Alliance). CCHIT has developed certification programs for

[17] Ibid.

both ambulatory (office-based) and inpatient (acute hospital) EHRs and is developing one for "systems that enable the exchange of information between health care providers"[18]

In some cases, interoperable software products including EMRs deployed to large collections of hospitals create a sort of mini-RHIO or HIE. RHIOs were not intended to develop this way, but the reality is that instead of having server farms that duplicate EMRs of patients in a particular area, RHIOs simply store the paths to find those records. In a study of 21 RHIOs, none stored their health records locally but instead used relative-complexity algorithms to match patient health records to particular patients across multiple healthcare institutions. The smallest RHIO studied provided 200,000 records, while the largest provided 5 million.[19] Because some healthcare institutions are so large, they have, in a sense, formed their own RHIO or HIE. The United States Department of Veterans Affairs (VA), for example, stores nearly 4.5 million Americans EMRs in a collection of data warehouses called VISNs. While there are some limitations on access, mainly due to security, the VISN system of the VA is a sort of RHIO.[20]

So far, RHIOs have developed out of government funding. RHIO equivalents have developed from large database networks necessary in large companies like Kaiser Permanente's HealthConnect. More recently, business employers have been involved with Personal Healthcare Records. Wal-Mart has joined forces with a few major companies to create Dossia[21], a company-maintained PHR system. Carolyn Walton, Vice President for Information Systems at Wal-Mart, assured the HHS that they will keep

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[18] United States Department of Health and Human Services: Certification Commission for Healthcare Information Technology, "Certification Handbook Ambulatory EHR Products 2007 Version 2.1 June 5, 2007," Certification Commission for Healthcare Information Technology, 2007, http://www.cchit.org/files/Ambulatory_Domain/2007AEHRCertificationHandbookV2_1.pdf [accessed August 13, 2007].

[19] E-HIM Work Group on Patient Identification in RHIOs, "Surveying the RHIO Landscape: A Description of Current RHIO Models, with a Focus on Patient Identification," *Journal of AHIMA* 77, no.1 (January 2006): 64A-D, http://www.ahima.org/e-him/ [accessed August 13, 2007].

[20] United States Department of Veterans Affairs, "Veterans Health Information Systems and Technology Architecture (VistA) – Description," http://www.virec.research.va.gov/datasourcesname/VISTA/VISTA.htm [accessed August 13, 2007].

[21] Dossia, http://www.dossia.org/home/ [accessed August 13, 2007].

employees medical records in confidence.[22] If successful, as many as 2.5 million people could have profiles on the new website. This will be a first case of a RHIO that is started based on a group of PHRs instead of a group of EMRs.

If software vendors seem excited about EMRs it is with good reason. No only is it profitable and beneficial for society as a whole, but it will unite health information resources in ways never before possible. If six children go to six different pediatricians with the same illness, the correlation will currently go unnoticed. With EMRs and bioterrorism software, the relationship can be recognized immediately and the source can be traced to bad food eaten in the same location the night before. "If you can't measure it, you can't improve it," say the software vendors. The technology has led to the field of bioinformatics, or using computers to solve problems involving large amounts of aggregate, usually genetic, data. EMRs can help us understand what genes have a higher disposition to cause cancer, for example. It would allow researchers and healthcare professionals to see how effective a particular drug was at curing a malady *nationwide* as opposed to just in the limited selection of patients available in their healthcare network. The availability of de-identified aggregate data on the health records of Americans for a mere ten years could have a significant impact on curing cancer.

That being said, it is likely that if the government finances RHIOs (or HIEs) and builds a NHIN, they will probably charge money to access it. On a recent slide from a presentation by Dr. Simon Cohn, chairman of the NCVHS, entitled "Excerpts from ONC Request for Assistance," is the statement "While quality measurement and reporting is a priority for HHS, there are other secondary uses for clinical data that could be of potential sources of revenues to Health Information Exchanges (HIEs). These generally fall into two categories: research and population health. Identifying requirements and articulating roles various entities play for data sharing, aggregation is needed along with how they

[22] Carolyn G. Walton, "Written Testimony of Carolyn G. Walton: Vice President – Information Systems Wal-Mart Stores, Inc. Before the Secretary of Health and Human Services' Public Advisory Body, the National Committee on Vital and Health Statistics, and the Subcommittee on Privacy and Confidentiality," National Committee on Vital and Health Statistics [January 23, 2007], http://www.ncvhs.hhs.gov/070123p1a.htm [accessed August 13, 2007].

address role-based access, control data release, and data stewardship."[23] The money charged would be directed to financing the HIEs, which have thus far relied on government funding.

Viewpoint of Healthcare Professionals and Healthcare Institutions

The responsibility for adopting EMR systems rests on the shoulders of the healthcare professionals themselves. More literature can be found on healthcare professionals and healthcare institutions adopting EMR systems than any other viewpoint. It seems for every success story there is a horror story. The result is that healthcare professionals who want to stay competitive know they have to adopt an EMR system, but so much information is available that making an educated decision about which one to choose requires more time than they have to spare. Because it is basically impossible for one person to gather all the facts, the choice of an EMR vendor should not be made by one person, even in a small practice. "Most experts agree that any practice or program looking to adopt EMRs first should establish an EMR task force."[24] The most successful, large-scale EMR implementations are based on this concept. Piedmont Healthcare in Atlanta, for example, has a panel of experts consisting of at least one doctor from each department and the CIO who meet once a week not only to make the decisions about which software solutions to roll out, but they are the only ones with access to the technology budget for the hospital network.

The main reason cited for not going paperless is cost. "Implementing an EMR system can run from $10,000 for small private practices to hundreds of thousands of dollars for larger practices depending on the EMR vendor."[25] Bills such as the Josie King Act and the Framework for Strategic Action promise funds for adopting interoperable EMR systems, but the reality is the government is not providing these funds. Just as the government did not help finance healthcare institutions when they conformed to HIPAA

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[23] Simon Cohn, "Draft Background for NCVHS Ad Hoc Work Group on Secondary Uses of Health Data," (slideshow, National Committee on Vital and Health Statistics, June 13, 2007). http://ncvhs.hhs.gov/070621p6.pdf [accessed August 13, 2007].
[24] Christian G. Downs, "Electronic Medical Records Mark a Landmark Shift in Record Keeping," *ONS News* 21, no. 4 [April 2006]: 9.
[25] Michelle Mostovy-Eisenberg, "Eye on EMRs: Implementation Obstacles," *Review of Ophthalmology* 13 no. 10 [October 2006]: 74.

requirements, it is not likely they will help out with EMR systems. Instead, the government is forcing the change by other means. "Physicians [by way of the healthcare institutions] who establish interoperable electronic health record systems in their practices can expect to be rewarded with increased compensation under the pay for performance policies being established at the Centers for Medicare and Medicaid Services (CMS)."[26] So basically, healthcare institutions that use EMRs get an additional percentage of their Medicare and Medicaid claims.

The unspoken main reason for not converting to EMRs is habit. Healthcare professionals who are used to carrying patient medical records in their pockets now have to use PDAs and Laptops. It is important in such transitions the medical staff start transcribing notes electronically as soon as the system is operable – the tendency will be to write notes on paper and type them in later which defeats the purpose.[27] Recent revisions by the HHS of the old Stark and Safe Harbor laws make it easier for healthcare institutions to convert to EMRs. "These new rules allow hospitals and other entities to give physicians computers, software, training and other services without violating the federal fraud and abuse laws."[28] Converting the old paper records to the new system can be time consuming.[29] The amount of radical change involved will leave the less technical-savvy employees behind; it is common that people lose their jobs when the transition to EMRs takes place because they can't keep up or refuse to adapt. It is also a slow process – it is not like flipping a switch to power on the new system, it's more like a series of stages, first making the medical records electronic (EMRs), then the prescriptions electronic, then the billing electronic and so on. The amount of work involved makes the adoption process daunting, and it is better to take it in small steps than get one massive system. It is quite common to use multiple software vendors for the different facets of the conversion process.

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[26] Bob Gatty, "CMS to reward practices with interoperable EMR systems," Dermatology Times 27 no. 7 [July 2006]:6.
[27] Clement J. McDonald, "The Barriers to Electronic Medical Record Systems and How to Overcome Them," *Journal of the American Medical Informatics Association* 4 no. 3 [May-June 1997]: 216.
[28] Michelle Mostovy-Eisenberg, "Eye on EMRs: Implementation Obstacles," *Review of Ophthalmology* 13 no. 10 [October 2006]: 74.
[29] Charles S. Reing, "Transitioning to EMR Takes Time But Pays Off," *Review of Ophthalmology* 13 no. 8 [August 2006]: 35.

There are also many non-government organizations that offer assistance in adopting medical records. They are too numerous to recognize but the leaders are member and trade organizations that consist of healthcare professionals donating their time and money to help each other solve common problems. The largest is the American Health Information Management Association (AHIMA)[30], which provides assistance to job seekers in the healthcare field, research grants, and maintains a site on personal health records. The American Medical Informatics Association (AMIA)[31] produces a journal with the latest developments in health care and bio-informatics, holds regular meetings, and provides networking tools for people in the healthcare industry. The Healthcare Information and Management Systems Society (HIMSS)[32] maintains a library of articles, research, and tools to help healthcare professionals adopt EMRs and software designers develop them.

The following information from the Center for Disease Control[33] demonstrates use of EMRs by office-based physicians:

Table 3: Percentage of Office-Based Physicians Who Report Using Electronic Medical Records: United States, 2001-05

Year	Percent
2001	18.2%
2002	17.3%
2003	17.3%
2004	20.8%
2005	23.9%

The results are from a poll, however. What would be more interesting is percentages provided by the CMS who actually pays healthcare institutions more money for using EMRs in the form of remuneration of Medicare and Medicaid claims.

[30] http://www.ahima.org/
[31] http://www.amia.org/
[32] http://www.himss.org/
[33] National Ambulatory Medicare Survey, "Electronic Medical Record Use by Office-Based Physicians: United States, 2005," Center for Disease Control, Figure 1, http://www.cdc.gov/nchs/products/pubs/pubd/hestats/electronic/electronic.htm [accessed August 13, 2007].

There is some degree of confusion among healthcare professionals as to what PHRs are. Certain software systems allow patients to log onto the network of the healthcare institution, usually via the Web, and see their health records. This is what was referred to previously as a "view PHR" – the patients are only reading selections of their EMR at the specific healthcare institution. True PHRs are health records designed by patients. If very few healthcare professionals know this it is because it is rare someone walks into their office with a USB device, CD or emails them a login for their information on a PHR website. The variety of formats PHRs can take adds to the confusion. Also, if the information is on a CD or USB device, it needs to be accessed on a computer that is not on the network to avoid potential viruses attacking the network, while logins for web sites have to be accessed by a computer with internet connectivity. Healthcare institutions have focused on making their different electronic systems interoperable. Even if a PHR program uses the HL7 CDA/CDD standard, it rarely can be lifted from the PHR system and dropped into the EMR system of the healthcare institution. "The full potential of PHR systems will not be realized until they are capable of widespread exchange of information with EHRs [electronic health records] and other sources of personal and other health data."[34]

Even if the PHR could be converted to an EMR, there is some concern about doing so. Patients say the main reason for being able to edit EMRs and/or PHRs is to avoid errors; on the other hand doctors do not want patients editing the information in these records. If a patient admits to their doctor they use cocaine on a daily basis, the doctor puts it in their EMR. Currently, the ability to read their "view PHR" or EMR at the medical institution causes complaints from patients who say "Why did you put that in there? Take that out!" Doctors stand their ground and say "No way." Healthcare professionals are concerned about patients being able to edit and control their record because they need all the available information to make a clinical decision about what diagnosis to make and what

[34] Workgroup on the National Health Information Infrastructure and the National Cancer Institute's Center for Bioinformatics. "Personal Health Records and Personal Health Record Systems." Washington DC: U.S. Department of Health and Human Services, [February 2006]. http://ncvhs.hhs.gov/0602nhiirpt.pdf [accessed August 13, 2007].

medications to prescribe. If patients can edit their healthcare record (whether it's a PHR or an EMR), how reliable can they be?

Healthcare institutions are reluctant to share their EMRs with other institutions. This leads to patients being referred out of the network of one healthcare institution and having to take the same tests all over again. From a legal perspective, healthcare institutions do not want to be responsible for making false diagnosis's based on insufficient data (the reason for the referral) which can be passed on to another healthcare institution. From a financial perspective, they feel that because they generated them, they own the patient's healthcare records. HIPAA requires the hospital to give the medical records to the patient upon request, and from there the patient can give them to the new provider. Often the medical records are in print format when given to the patient, meaning they would have to be typed in manually, or scanned into the new providers system.

The push to adopt EMRs in healthcare institutions is pitting healthcare professionals against their patients. Patients have never before had access to their health records; gone are the days when a healthcare professional could write a note in the margin of a patient's health record "Not very nice," or "Smells bad." The industry has forced healthcare professionals to be, well, professional about what they write. Healthcare Professionals already undergo extensive schooling to hold the jobs they have, they have to be right about their diagnosis all the time to avoid law suits, and they now have to become information technology specialists to adapt to the changes in the marketplace. For many of them the demands are excessive and the rewards are slight. More recognition needs to be conveyed to the healthcare professionals as individuals rather than the medical facility they work for. Organizations such as AHIMA help keep healthcare professionals informed about industry changes in medicine and technology, and for the healthcare executives there are conferences to go to and standards to monitor.

Conclusion

It is very important to realize there is a chain of communication here. The healthcare professionals join these organizations that make the studies and recommend the standards. The government issues the standards and the software companies follow them. While it may take some time for the inertia to complete the circuit, it is happening and things are getting done.

The concept of the RHIO has been replaced by the HIE. The government needs to give more power to HIEs and let them choose how they want to have EMRs reported to them so they can create Tethered PHRs that the consumer can then log in and modify. This takes the responsibility for creation and maintenance out of the hands of the individual patient, but gives them the ability to adjust and hide certain information. This is important because some people will be less likely to maintain a PHR, such as people who suffer from depression or anxiety; others may be incapable of maintaining their own PHR due to disability. It would be secured with a login over a 128-bit encryption over the internet. It would allow patients to see their entire record, and "hide" specific doctors visits and health information to customize a "view", but would not actually erase them. They could customize a PHR "view" with a new login and password they could then give to a doctor before an appointment so the healthcare professional could then download that specific set of medical files in a secure transaction. Furthermore, there needs to be a provision for family members to access the PHRs of relatives who are incapable of maintaining their own PHR for medical reasons. Most importantly, it would standardize the way PHRs are stored because the way EMRs are stored is currently standardized.

Currently HIEs and RHIOs store links to where in their network a particular patient's EMRs can be found. The HHS plan for the NHIN is likewise a plan for a "network of networks" rather than a centralized database of EMRs. If the NHIN plans to sell access to their information for research purposes, however, the bandwidth of the queries will be on the healthcare institutions themselves because the system architecture will undoubtedly rely on the efficiency of the HIEs who should expect some sort of financial aid or

remuneration. Conversely, smaller entities with limited databases that comprise the HIE should not expect financial compensation for converting to EMRs, even though it has been promised.

If the United States government intends to use the NHIN to track potential cases of bioterrorism and simultaneously give citizens the opportunity to “opt-out” there is going to be some difficulty drawing valid conclusions in time to contain an actual attack. Also, the initial NHIN is going to be limited to EMRs and PHRs. Ideally, everything about a person would be stored with the EMR, including X-Rays and DNA charts, but this can total 600 MB per person or more. When the industry has caught up, bioinformaticians could use the NHIN to find genetic predispositions for cancer and other diseases across the entire US population (for example) but the current plan for a NHIN is just a basic EMR/PHR package. Despite this limitation, the NHIN is fast becoming a reality and the Framework for Strategic Action can be realized by 2014.

Glossary of Acronyms and Organization Websites

AHIMA. American Health Information Management Association – an organization for healthcare professionals and job seekers. www.ahima.org

AMIA. American Medical Informatics Association – an organization for healthcare professionals that publishes a journal. www.amia.org

ANSI. American National Standards Institute – a for-profit entity that creates standards for a variety of industries. Created a standard for medical records called the Clinical Care Record (CCR) www.ansi.org. See also HL7.

ASIC. American Health Information Community – A branch of the Department of Health and Human Services composed of healthcare executives who advise the Office of the National Coordinator. www.hhs.gov/healthit/community/background/

ASTM. American Society for Testing and Materials – the first standards institute in America, now part of ANSI.

CCHIT. Certification Commission for Healthcare Information Technology – a certification program for software companies to establish their product as compliant with the government requirements for electronic health records. www.cchit.org

CMS. Centers for Medicare and Medicaid Services – a branch of the Department of Health and Human Services that deals with Medicare and Medicaid. www.cms.hhs.gov

DICOM. Digital Imaging and Communications in Medicine – a digital imaging standard for storing and cataloging medical images.

EMR. Electronic Medical Record

EHR. Electronic Health Record, synonymous with EMR

HHS. The Department of Health and Human Services – a governmental department of the United States of America that monitors the health of its citizens. It encompasses Medicare and Medicaid, the Department of Veterans Affairs, and many other departments mentioned in this paper. www.hhs.gov

HIE. Health Information Exchange – also called HIEI – a revision of the term RHIO that is preferred because it indicates the EMRs will be shared across a network as opposed to being stored in a central hub.

HIEI. Health Information Exchange and Interoperability – synonymous with HIE.

HIT. Health Information Technology – an abbreviation used by the Office of the National Coordinator. See also CCHIT.

HIMSS. Healthcare Information Management Systems Society – an organization for healthcare professionals seeking grants and research information. www.himss.org

HIPPA. Health Insurance Portability and Accountability Act of 1996

HL7. Health Level 7 – both a standard and a standards organization responsible for medical standards know as HL7 CDA, or Clinical Document Architecture. www.hl7.org

HL7 CDA/CCR. Health Level 7 Clinical Document Architecture / Clinical Care Record – a standard in progress that unifies the Health Level 7 Clinical Document Architecture with the ASTM Clinical Care Document slated for release in 2009.

ONC. Office of the National Coordinator – a branch of the Department of Health and Human Services that was established by George Bush for the purpose of making all health records electronic by 2014. www.hhs.gov/healthit/

PHR. Personal Health[care] Record or Patient Health Record. a term from the Department of Health and Human Services (HHS) Office of the National Coordinator (ONC) report "Framework for Strategic Action." It is an EMR that is owned by the patient and the patient controls access and content.

NCVHS. National Committee on Vital and Health Statistics – a branch of the Department of Health and Human Services (HHS) www.ncvhs.hhs.gov

NHII. National Health Information Infrastructure – a branch of the Department of Health and Human Services responsible for approving medical standards. aspe.hhs.gov/sp/NHII/

NHIN. National Health Information Network – a term from the Department of Health and Human Services (HHS) Office of the National Coordinator (ONC) report "Framework for Strategic Action." The goal of the NHIN is to unify all RHIOs – now called HIEs – into one master database.

RHIO. Regional Healthcare Information Organization – a term from the Department of Health and Human Services (HHS) Office of the National Coordinator (ONC) report

"Framework for Strategic Action" meaning a collection of links to electronic medical records (EMRs) in a particular geographic region.

VISN. Veterans Integrated Service Network – the "RHIO" for the Department of Veterans Affairs. www.va.gov

XML. extensible markup language – a text-based method of organizing information that was used as the basis for (among other things) web pages on the internet.

Bibliography

Brailer, David J. “National Coordinator for Health Information Technology; Development and Adoption of a National Health Information Network.” *Department of Health and Human Services Federal Register* 69, no. 219 [November 15, 2004]: 65599.

Cohn, Simon. “Draft Background for NCVHS Ad Hoc Work Group on Secondary Uses of Health Data.” Slideshow, National Committee on Vital and Health Statistics, June 13, 2007, http://ncvhs.hhs.gov/070621p6.pdf [accessed August 13, 2007].

_____. Letter to Michael Leavitt September 9, 2005. *Department of Health and Human Services National Committee on Vital and Health Statistics*. http://www.ncvhs.hhs.gov/050909lt.htm [accessed August 13, 2007].

Downs, Christian G. “Electronic Medical Records Mark a Landmark Shift in Record Keeping.” *ONS News* 21, no. 4 [April 2006]: 9.

E-HIM Work Group on Patient Identification in RHIOs. "Surveying the RHIO Landscape: A Description of Current RHIO Models, with a Focus on Patient Identification." *Journal of AHIMA* 77, no.1 (January 2006): 64A-D. http://www.ahima.org/e-him/ [accessed August 13, 2007].

Gatty, Bob. “CMS to reward practices with interoperable EMR systems.” Dermatology Times 27 no. 7 [July 2006]:6-7.

Kennedy, Patrick J. “Kennedy Josie King Act (H.R. 4880)” Rhode Island Representative Patrick J. Kennedy Campaign Website. http://patrickkennedy.house.gov/ [accessed August 14, 2007]

Kohn, Linda T. and Corrigan, Janet M. and Donaldson Molla S., eds. *To Err Is Human: Building a Safer Health System*. Washington DC: National Academies Press, 2000.

McDonald, Clement J. "The Barriers to Electronic Medical Record Systems and How to Overcome Them" *Journal of the American Medical Informatics Association* 4 no. 3 [May-June 1997]: 213-221.

[McInturff, Bill?]. "Attitudes of Americans Regarding Personal Health Records and Nationwide Electronic Health Information Exchange. Key Findings From Two Surveys of Americans." Alexandria, VA: Public Opinion Strategies survey for the Markle Foundation, 2005.

Mostovy-Eisenberg, Michelle. "Eye on EMRs: Implementation Obstacles." *Review of Ophthalmology* 13 no. 10 [October 2006]: 73-80.

National Ambulatory Medicare Survey. "Electronic Medical Record Use by Office-Based Physicians: United States, 2005." Center for Disease Control. http://www.cdc.gov/nchs/products/pubs/pubd/hestats/electronic/electronic.htm [accessed August 13, 2007].

Prosocial Applications, Inc. "What's So Special About the Caregiver PHR?" caregiveralliance.com. http://www.thesmartphr.com/docs/Whats-So-Special-about-the-Caregiver-PHR.pdf [accessed August 13, 2007].

Reing, Charles S. "Transitioning to EMR Takes Time But Pays Off." *Review of Ophthalmology* 13 no. 8 [August 2006]: 34-35.

Rishel, Wes and Riehl, Virginia and Blanton, Cathleen. “Summary of the NHIN Prototype Architecture Contracts.” Department of Health and Human Services: Office of the National Coordinator for Health Information Technology, 2007. http://www.hhs.gov/healthit/healthnetwork/resources/summary_report_on_nhin_Prototype_architectures.pdf [accessed August 13, 2007].

Thompson, Tommy G. and Brailer, David J. “The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Healthcare Framework for Strategic Action.” *Department of Health and Human Services* [July 21, 2004]. http://www.hhs.gov/healthit/documents/hitframework.pdf [accessed August 13, 2007].

United States Department of Health and Human Services: Certification Commission for Healthcare Information Technology. “Certification Handbook Ambulatory EHR Products 2007 Version 2.1 June 5, 2007.” Certification Commission for Healthcare Information Technology, 2007. http://www.cchit.org/files/Ambulatory_Domain/2007AEHRCertificationHandbookV2_1.pdf [accessed August 13, 2007].

United States Department of Veterans Affairs. “Veterans Health Information Systems and Technology Architecture (VistA) – Description.” http://www.virec.research.va.gov/datasourcesname/VISTA/VISTA.htm [accessed August 13, 2007].

U.S. President. Executive Order no. 13335, “Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator.” *Federal Register* 69, no. 84 [April 27, 2004]: 24059. http://www.whitehouse.gov/news/orders/ [accessed August 13, 2007].

Walton, Carolyn G. “Written Testimony of Carolyn G. Walton: Vice President – Information Systems Wal-Mart Stores, Inc. Before the Secretary of Health and Human Services’ Public Advisory Body, the National Committee on Vital and Health Statistics, and the Subcommittee on Privacy and Confidentiality.” National Committee on Vital and Health Statistics [January 23, 2007]. http://www.ncvhs.hhs.gov/070123p1a.htm [accessed August 13, 2007].

Workgroup on the National Health Information Infrastructure and the National Cancer Institute’s Center for Bioinformatics. “Personal Health Records and Personal Health Record Systems.” Washington DC: U.S. Department of Health and Human Services, [February 2006]. http://ncvhs.hhs.gov/0602nhiirpt.pdf [accessed August 13, 2007].